

Has patient knowledge of Inflammatory Bowel Disease improved since 1999 ?

Richard Anthony Wardle¹, John Francis Mayberry²

(1) The Gastrointestinal Research Unit, Leicester General Hospital, United Kingdom ; (2) Department of Digestive Diseases, University Hospitals of Leicester NHS Trust, UK.

Abstract

Background : In the UK Inflammatory Bowel Disease (IBD) Standards have highlighted the importance of patient education and support [1]. Little literature exists however regarding the impact of these standards on patient's understanding of their disease.

Aim : To utilise the Crohn's and Colitis Knowledge Score (CCKNOW) to assess patient knowledge and make a comparison with results achieved in 1999. To assess whether disease CCKNOW scores differ between white and Asian populations in Leicestershire.

Methodology : 100 outpatients with CD or UC were prospectively enrolled to complete the CCKNOW questionnaire between May and September 2013 at two Leicestershire Hospitals.

Results : Mean and median scores for IBD patients were 10.15 (95% C.I. 9.2-11.1) and 9 (95% CI 8-11) respectively. CD (38) patients achieved a significantly higher score than UC (61), median scores of 10.5 and 9 respectively, $p = 0.007$. CCKNOW scores achieved were significantly lower with increasing age, $p = 0.0006$. Patient ethnicity, gender, disease duration or perceived disease activity had no significant effect upon CCKNOW score.

Conclusion : Patient understanding of inflammatory bowel disease is no better now than when assessed in 1999, median scores being 9 and 10 respectively. There are persisting knowledge deficits regarding the subjects of fertility and the complications of IBD. CCKNOW scores achieved were significantly lower with increasing age, elderly patients may therefore benefit the most from increased access to appropriate educational programmes and support. (*Acta gastroenterol. belg.*, 2015, 78, 381-385).

Key words : CCKNOW, inflammatory bowel disease, Crohn's disease, ulcerative colitis, Patient education, and Patient knowledge.

Introduction

In the UK, key professional organisations have collaborated to provide Inflammatory Bowel Disease (IBD) Standards to be delivered by the National Health Service (NHS), highlighting the importance of patient education and support (1). Little literature exists however regarding the impact of these standards on patient's knowledge of their disease. This study aims to assess the existing level of patient understanding and make a comparison with that achieved in 1999, in order to evaluate the influence of recent interventions.

There are two major forms of IBD, Crohn's disease (CD) and ulcerative colitis (UC), both of which are chronic inflammatory conditions affecting the gastrointestinal tract. Diagnosis is usually made in early adult life and both follow a relapsing and remitting course, meaning high costs for IBD patients and society as a result of extensive laboratory tests, procedures, hospitalisation and surgery (2-4). The highest incidence rates are traditionally reported in Northern and Western Europe as well

as North America. Lower rates are found in Africa, South America and Asia, including China (5,6). Empowering IBD patients to manage their own condition has been shown to result in fewer hospital visits without an increase in the number of primary care visits, a finding with significant benefits considering the economic consequence of the disease (2-4,7). Improving patient's knowledge may also facilitate the use of more adaptive coping strategies, another benefit as evidence suggests IBD patients have significantly poorer psychological health and view their general health more negatively than non-sufferers (8,9). Within the Leicester NHS Trust, a number of specific educational interventions have been implemented since 1999 to encourage patient education and support. Gastroenterology departments have provided the following : a free of charge series of booklets on inflammatory bowel disease (covering symptoms, associated diseases, investigations, treatment and pregnancy), a free induction pack to all newly diagnosed patients, a nurse counselling service available both face to face and by telephone and also active encouragement to join a local self-help group with a national web based information program and local educational meetings.

The Crohn's and Colitis Knowledge Score (CCKNOW) is a questionnaire developed to assess the effectiveness of educational interventions for patients with IBD (10). Developed by Eaden *et al.* in 1999 the CCKNOW consists of 24 multiple-choice questions divided into five areas, general knowledge (8), anatomy (4), medications (5), diet (2) and complications (5). Scoring of the questionnaire is one point for each correct answer with no negative marking. Following validation, the CCKNOW was completed by 354 UC and CD patients on the Leicestershire IBD database reporting a median score of 10 (95% C.I. = 9 to 10) (10). Recognised statistical tests have shown the CCKNOW to be a valid, reliable and readable questionnaire and it has been embraced internationally, fuelling research into educational tools and measures of patient and staff IBD understanding (11).

The primary aim of this study is to assess the existing level of patient understanding and make a comparison

Correspondence to : Dr Richard Anthony Wardle, MBChB, MrPharm, 27 South Copse, East Hunsbury, Northampton, NN4 0RY, UK.
E-mail : Richardwardle@hotmail.com

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with that achieved in 1999. It is expected that the median CCKNOW score within the Leicestershire population will be no better than when assessed in by 1999 by Eaden *et al.* (10). This hypothesis is based upon previous use of the CCKNOW in the UK (11-13). The major criticism of this evidence is that surveys were based in the North-West and Pennine areas of England, and not Leicestershire the site of the original study. Patient performance in the five knowledge areas assessed by the CCKNOW will also be analysed in detail. Previous studies have highlighted particular weaknesses in knowledge surrounding fertility and implications regarding pregnancy (10,13). As a secondary aim, the relationship between CCKNOW score and patient ethnicity, age, sex, diagnosis, disease duration and disease activity will be assessed. The South Asian ethnic group makes up 28.3% of Leicester's population, much higher than the average in England and Wales of 2.5% (14). There are very few patients with IBD in Leicester of either African or Afro-Caribbean origins. Research has highlighted potential bias in practice against ethnic minorities that may exist within the NHS therefore this study will also seek to assess whether disease CCKNOW scores differ between the white and Asian populations (15,16).

Methodology

The study was conducted across Leicester General Hospital and Market Harborough and District Hospital. Patients with CD or UC were prospectively enrolled between May and September 2013 whilst in the waiting area for their outpatient appointment. Those under 18, too ill to participate or not willing to complete the questionnaire were excluded. Prior to enrolment informed consent was obtained. To prevent outside help on completing the questionnaire, participants were advised to complete it within the outpatient department, not to use any form of literature source and also not to discuss any part of the questionnaire with another person. To reduce selection bias, eligible patients were enrolled sequentially according to the routine waiting list at the clinic. Recruitment continued until 100 patients had completed the questionnaire.

The questionnaire consisted of two parts. The first part recorded patient ethnicity, diagnosis, year of diagnosis and also a self-assessed rating of disease activity. The second part of the questionnaire included a 24-item

CCKNOW assessment. One point was awarded for each correct answer with no negative marking. Results were then analysed using the StatsDirect (2013) and SYSTAT (2013) statistical packages.

Results

The participation rate was 89% (100 out of 112 patients). 61 patients had UC and 38 patients CD, and one patient reported a diagnosis of both. 58 females with a mean age of 49.2 (range 18-75) and 42 males with a mean age of 47.1 (range 18-77) completed the questionnaire. 73 patients were white Europeans and 27 Asian. Mean disease duration in females was 12.2 (range 0-39) years and in males 13.3 (range 0-41) years.

The mean and median scores for IBD patients were 10.15 (95% C.I. 9.2-11.1) and 9 (95% CI 8-11) respectively. The strongest knowledge area was questions relating to diet, and the weakest questions relating to disease complications (Table 1). CD patients achieved a significantly higher score than UC patients with median scores of 10.5 and 9 respectively, $p = 0.007$. Median scores for White European and Asian patients were both 9. The median score for females was 10.5 and for males 8.5 though this difference was not significant, $p = 0.08$. The effect of age upon average CCKNOW score was found to be statistically significant, correlation coefficient ($r = -0.344412$, $p = 0.0006$ (Fig. 1). The highest median score of 14 was achieved by the 30-39 age group, whilst the lowest median score of 7 was in the 70-79 age group. Disease duration or perceived disease activity did not correlate significantly with CCKNOW score.

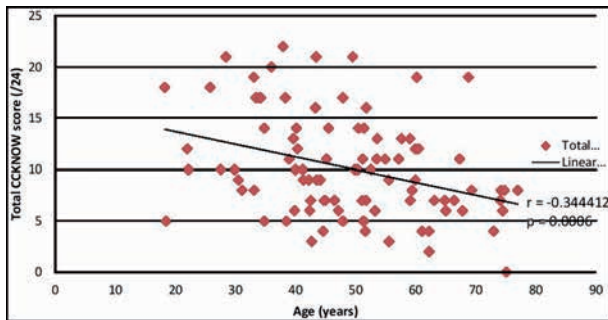
Discussion

With the specific educational interventions practised in the Leicester NHS Trust, the growing role of IBD specialist nurses and the increase in accessibility to information on the worldwide web, it would be reasonable to expect that general knowledge amongst IBD patients may have improved since 1999 (1,17-19). However CCKNOW questionnaire performance in Leicestershire was no better than when assessed in 1999, median scores being 9 and 10 respectively (Table 2). This echoes results recently achieved using the CCKNOW in the North-West of England where the median score was 9 and in the Pennine Trust where it was 7 (12,13).

Table 1. — Knowledge areas assessed by the CCKNOW

Knowledge Area	Related question no.	Mean % Correct Answers
General Knowledge	4-6, 9, 15, 18, 19, 23	48.3
Anatomy	3,8,17,22	34.8
Medications	10-13,16	46
Diet	1,2	57.5
Complications	7, 14, 20, 21, 24	29

Mean % correct answers divided by knowledge areas. General knowledge (8), anatomy (4), medications (5), diet (2) and complications (5).



There was a decrease in CCKNOW score with patient age. The relationship was statistically significant, correlation coefficient (r) = -0.344412, p = 0.0006.

Fig. 1. — Patient Age vs. Total CCKNOW Score

The educational interventions practised in the Leicester NHS Trust may explain why scores were higher than those achieved in the Pennine Trust. However to explain why overall patients from across the UK are not achieving higher CCKNOW scores it is useful to observe the results of the UK IBD audit (20). When services were compared to the IBD standards for education and support, only 65% (15/23) of UK sites provided educational opportunities for patients. 39% (9/23) of sites failed to provide information on IBD in different languages, which in areas such as Leicestershire may exclude large sections of the community (21). At least one in ten patients reported sub-optimal aspects of discharge information about drug side-effects, warning signs to watch for, or how to manage their condition once home (21). Additionally, whilst evidence exists for the impact of specialist IBD nurses within a department, many sites still have less than one and a half nurses per 250,000 population as recommended in the IBD Standards (21-24). The Royal College of Nursing (RCN) IBD nursing audit found that 45% of IBD specialist nurses that responded did not hold a basic level of degree, so their ability to teach patients effectively may also be questioned (25). These statistics provide a national picture of potential service failings. Within the Leicester NHS Trust itself it is noticeable that standardisation of waiting areas across the trust has led to the removal of previously accessible educational material such as posters and educational videos. This is unfor-

tunate as it has been shown that patients prefer such information, particularly in the form of a video (26-29).

Areas of particular deficit highlighted were found in the subjects of fertility and complications of IBD. Specifically 79% of patients (76% of women) were unaware that women with CD may find it more difficult to become pregnant. Just 14% of patients (21% of men) were aware that sulfasalazine may cause reduced fertility levels in men which are reversible on stopping medication. Current National Institute for Health and Care Excellence (NICE) guidance highlights fertility and sexual relationships as areas where additional information should be provided to CD patients (30). Similar weaknesses have been raised by previous studies (31,32). This may reflect the conflicting clinical evidence available in these areas or hesitancy in broaching such sensitive topics (33). Regarding screening of IBD patients for cancer of the colon 85% of patients were unaware which patients would be at increased risk. Interestingly all of mentioned deficits were highlighted in 1999 by Eaden *et al.* and in 2011 by the study based in Pennine Trust but it seems that no improvements have been made (10,13).

Patient ethnicity, sex, disease duration and disease activity had no significant effect on the CCKNOW score achieved. However, a significant relationship was found between increasing age and decreasing CCKNOW score (Fig. 1), peak knowledge being in the 30-39 age group. Elderly IBD patients may therefore benefit the most from increased access to appropriate educational programmes and support (34-37). Why CD patients in this survey achieved significantly higher scores than those with UC is difficult to explain and has not been a feature in previous surveys within the UK. One reason could be the lower mean age of CD participants (CD 46 years, UC 50 years) in this study, again suggesting the importance of patient age upon questionnaire performance. However other unmeasured confounders such as educational level, employment status and National Association for Colitis and Crohn's Disease (NACC) membership must also be considered.

Limitations

The small size of the study population and its restricted geographical coverage are the survey's noticeable weaknesses. Patient educational level, employment status and

Table 2. — Comparison with 1999 study

	Leicestershire, Eaden <i>et al.</i> 199910	Leicestershire, 2013
Number of Completed CCKNOW Questionnaires (response rate %)	354 (55)	100 (89)
UC (%)	200 (56)	61 (61)
Crohns (%)	154 (44)	38 (38)
Median Score (95% C.I.)	10 (9 -10)	9 (8 -11)

Comparison with study carried out in 1999 by Eaden *et al.*

NACC membership status are potential confounders that were not measured.

The CCKNOW questionnaire itself was criticized by patients due to its high difficulty and also the clinical relevance of some of its questions, for example including four questions relating to gastrointestinal anatomy. Question 12 relates specifically to the use of sulfasalazine which is now not a first line treatment, an inaccuracy which may have put patients completing the CCKNOW more recently at a disadvantage. These issues highlight the requirement for a more clinically relevant and up to date knowledge questionnaire for the IBD population. Despite these limitations the CCKNOW remains the only available questionnaire to carry out such studies, and further research is required if we are to ever fully understand whether there are real clinical benefits for seeking to improve patient knowledge in IBD.

Conclusion

The introduction of IBD standards, IBD specialist nurses and the technological advances in access to the world wide web seem to be having little effect on patients overall understanding of IBD. The use of the CCKNOW in the UK to date has highlighted that IBD patients understanding of their disease is no better than in 1999. It has also found persisting knowledge deficits regarding the subjects of fertility and the complications of IBD. Gastroenterology departments may improve by focusing on areas highlighted by the UK IBD audit, providing additional support for educating elderly patients and optimising information available in outpatient waiting room facilities. Regular use of the CCKNOW in patients awaiting outpatient appointments may also highlight to the clinician those who would benefit most from additional educational interventions.

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